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RESEARCH ARTICLE

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Cost-consequence analysis of an intervention for the management of neuropsychiatric symptoms in young-onset dementia: Results from the BEYOND-II study

Jeannette C.L. van Duinen-van den IJssel^{1,2}  | Christian Bakker^{1,2,3} | Martin Smalbrugge⁴ | Sandra A. Zwijsen⁴ | Eddy Adang⁵ | Britt Appelhof^{1,2,6}  | Sytse U. Zuidema⁷ | Marjolein E. de Vugt⁸ | Frans R.J. Verhey⁸ | Raymond T.C.M. Koopmans^{1,2,9}

¹ Department of Primary and Community Care, Radboud University Medical Center, Radboud Institute for Health Sciences, Nijmegen, The Netherlands

² Radboud Alzheimer Center, Radboud University Medical Center, Nijmegen, The Netherlands

³ Groenhuysen, Center for Geriatric Care, Roosendaal, The Netherlands

⁴ Department of General Practice and Elderly Care Medicine/Amsterdam Public Health Research Institute, Amsterdam UMC, Amsterdam, The Netherlands

⁵ Department for Health Evidence, Radboud University Medical Center, Radboud Institute for Health Sciences, Nijmegen, The Netherlands

⁶ Archipel Care Group, Landrijt, Center for Specialized Care, Eindhoven, The Netherlands

⁷ Department of General Practice and Elderly Care Medicine, University of Groningen, University Medical Center Groningen, Groningen, The Netherlands

⁸ School for Mental Health and Neuroscience, Alzheimer Center Limburg, Maastricht University Medical Center, Maastricht, The Netherlands

⁹ De Waalboog, "Joachim en Anna", Center for Specialized Geriatric Care, Nijmegen, the Netherlands

Correspondence

Christian Bakker, MSc, PhD, Primary Care Department, Radboud University Medical Center, PO 9101, 6500 HB Nijmegen (route 117), The Netherlands.
Email: christian.bakker@radboudumc.nl

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Objective: To evaluate the cost-consequences of an intervention for the management of neuropsychiatric symptoms in nursing home residents with young-onset dementia.

Methods: A stepped wedge design was used. The intervention consisted of an educational program and a multidisciplinary care program and was implemented in 13 nursing homes from September 2015 to March 2017. Costs' outcomes included the time investment of the elderly care physician and health care psychologists regarding the management of neuropsychiatric symptoms, residents' psychotropic drug use, nursing staff absenteeism, and costs of the educational program. Composite cost measure contained the sum of costs of staff absenteeism, costs on psychotropic drugs, and costs of the educational program. Costs of time investment were investigated by comparing means. Costs of psychotropic drug use were analyzed with mixed models at resident level and as part of the composite cost measure on unit level. Staff absenteeism was also analyzed at unit level.

Results: Compared with care as usual, the mean costs of time invested decreased with €36.79 for the elderly care physician but increased with €46.05 for the health care psychologist in the intervention condition. Mixed model analysis showed no effect of the intervention compared with care as usual on the costs of psychotropic drug use, staff absenteeism, and the composite cost measure. The costs of the educational program were on average €174.13 per resident.

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Conclusion: The intervention did not result in increased costs compared with care as usual. Other aspects, such as the lack of a structured working method, should be taken into account when considering implementation of the intervention.

KEYWORDS

cost-consequence analysis, neuropsychiatric symptoms, nursing home, psychosocial intervention, young-onset dementia

1 | INTRODUCTION

The prevalence of dementia worldwide is around 50 million and is expected to rise to 75 million people¹ in 2030. According to the WHO, the costs of dementia care worldwide were 818 billion US dollars in 2015 and are expected to rise to 2 trillion US dollars in¹ 2030. In the Netherlands, currently 270 000 people have dementia of which 70 000 people live in long-term care facilities, and this is expected to increase.² The costs for care for people with dementia living in long-term care facilities in the Netherlands were 5.19 billion US dollars² in 2015, and this will likely increase in the upcoming years. Of all the people with dementia, about 6% to 9% develop the first symptoms before the age of 65, which is the so-called young-onset dementia (YOD).³ In the Netherlands, approximately 12 000 people have YOD.²

Research shows that one of the important cost-drivers of nursing home care is related to the presence of neuropsychiatric symptoms (NPS).⁴ Indeed, NPS are highly prevalent in nursing home residents with late-onset dementia⁵ resulting in negative health consequences for the resident such as lower quality of life⁶ and higher psychotropic drug use⁷ and higher levels of nursing staff burden.⁸ Increased burden in the nursing staff may lead to lower job satisfaction, burn-out complaints, and absenteeism, further increasing health care costs.^{4,8-12} Furthermore, caring for someone who shows NPS may be more time-consuming, and consequently, there may be less time for other residents. This may put a strain on quality of care. Although research on YOD nursing home residents is scarce, research thus far shows that NPS are present in nearly 90% of residents^{13,14} and is associated with lower quality of life of the resident¹⁵ and high levels of nursing staff burden.¹⁶ Furthermore, almost 88% of the nursing home residents with YOD use psychotropic drugs.¹³

In the Netherlands, nursing home residents with YOD reside on special care units (SCUs) because they have specific care needs regarding daytime activities, social contacts, and mobility.^{17,18} Care is provided by a multidisciplinary team, consisting of an elderly care physician,¹⁹ health care psychologist, and nursing staff, all with specific expertise on care and treatment of YOD.

Regarding the management of NPS, there was no specific intervention for YOD nursing home residents available. Therefore, in the BEYOND-II study, an intervention was developed aimed at the management of NPS in YOD nursing home residents.²⁰ This was based on an intervention that was effective in nursing home residents with late-onset dementia.²¹ The intervention consists of an educational

Key points

- Costs of psychotropic drug use and staff absenteeism did not differ between the use of the intervention and care as usual.
- An average cost of time invested on the management of neuropsychiatric symptoms decreased for the elderly care physician but increased for the health care psychologist in the intervention condition.
- The intervention is of interest for nursing homes in need for a methodological and multidisciplinary approach towards the management of neuropsychiatric symptoms in nursing home residents with young-onset dementia.

program and a care program that focuses on a multidisciplinary and systematic management of NPS in YOD. The aim was to reduce NPS and psychotropic drug use, which may also result in decreased work-related burden and absenteeism in nursing staff. It was the first intervention developed specifically for the management of NPS in nursing home residents with YOD. The use of the intervention was equally effective as care as usual in terms of the prevalence of neuropsychiatric symptoms and psychotropic drug use as well as nursing staff burn-out, job satisfaction, and job demands.^{22,23} Given these findings, the intervention should be equally or less costly as usual care to warrant implementation. Therefore, it is important to gain insight in costs of the intervention to provide information to health care decision makers for more rational decision making. We performed a cost-consequence analysis for estimating the value for money of the intervention, in which the costs and consequences are presented in a disaggregated format.²⁴ The aim of this study was to compare the costs and the consequences of the intervention for the management of NPS with nursing home care as usual.

2 | METHODS

2.1 | Design

A cost-consequence analysis was performed alongside a cluster-randomized controlled trial which lasted from September 2015 to April 2017. The details of this trial are described elsewhere.²⁰ Cluster

randomization was used because the intervention was implemented at the staff level. A stepped wedge design was used to evaluate the effect of the care program for the following reasons. It allows all clusters (in this case, groups of YOD special care units) to cross over from the control to the intervention condition over time, assuring that all units receive the intervention at the end.²⁵ This increases motivation for clusters to enroll and stay in the study. Also, training of the clusters' staff could be stepwise by cluster over time instead of providing training to half of the clusters at once as in two-arm trial. Furthermore, several designs were compared in terms of power at the design stage, and a stepped wedge trial was likely the most powerful for the scenarios envisaged. Thirteen YOD SCUs were randomly divided across three groups, with two groups of four and one group of five YOD SCUs. There were four assessments at 6-month intervals during a period of 18 months. After the baseline assessment, the first group started working according to the care program, and from then on after each assessment, a new group entered the intervention condition. YOD SCUs in the control condition continued to offer care as usual. At the last assessment, all SCUs were in the intervention condition.

2.2 | Participants

YOD SCUs were recruited through nursing homes affiliated with the Dutch YOD Knowledge Center. People with YOD who had a diagnosis of dementia with symptom onset before the age of 65 and who had been residing in the SCU for at least 1 month were included in the study. People with dementia caused by human immunodeficiency virus (HIV), traumatic brain injury, Down syndrome, Korsakov or Huntington disease were excluded from the study. If a resident moved from the unit or died, a newly admitted resident was invited to participate in the study. All nurses employed in the YOD SCU were invited to participate in the study, irrespective of educational level and hours of employment.

2.3 | Intervention

The development of the intervention "Grip on NPS in institutionalized people with YOD" is described in full detail elsewhere.²⁶ The first 2

months of the intervention covered the educational program and a start-up phase for learning to work with the care program (Figure 1). During this period, the elderly care physician completed the first step of the care program by using a tool for the evaluation of the appropriateness of psychotropic drug prescription for NPS that was derived from the Appropriateness of Psychotropic Drug Prescription In Dementia (APID) instrument.²⁷ After this initial evaluation, the physicians could decide to perform a reevaluation at their own discretion. After the first 2 months, the multidisciplinary team started with the four circular steps: detection, analysis, treatment, and evaluation. The detection of symptoms of NPS could take place during nurses' usual daily observations or every 6 months with a screening tool by the vocational nurse. After detection of NPS, nurses performed an analysis of possible causes of NPS and presence of unmet needs by means of a needs assessment tool that was derived from the Dutch version of the Camberwell Assessment of Need for the Elderly.²⁸ The analysis was continued by the elderly care physician or psychologist. The outcome of the analysis and the options for treatment were discussed in multidisciplinary meetings, and a treatment plan was established. The treatment plan consisted of a description of the frequency and severity of the current NPS and the aim in terms of frequency and severity of the NPS. The intervention did not prescribe a specific treatment as this is based on the specific causes of NPS. In line with the guidelines, psychosocial treatments were preferred above treatment with psychotropic drugs. The treatment was evaluated by comparing the frequency and severity of NPS before and after treatment. If the results of the evaluation were unsatisfactory, the analysis could be redone, or another treatment could be considered, else the detection phase would start again. All steps of the care program were supported by digital forms. After 6 months, a follow-up training took place.

2.4 | Care as usual

Residents not receiving the intervention received care as usual. Care as usual regarding NPS is less structured compared with the intervention and often consists of the following steps: The nurse consults

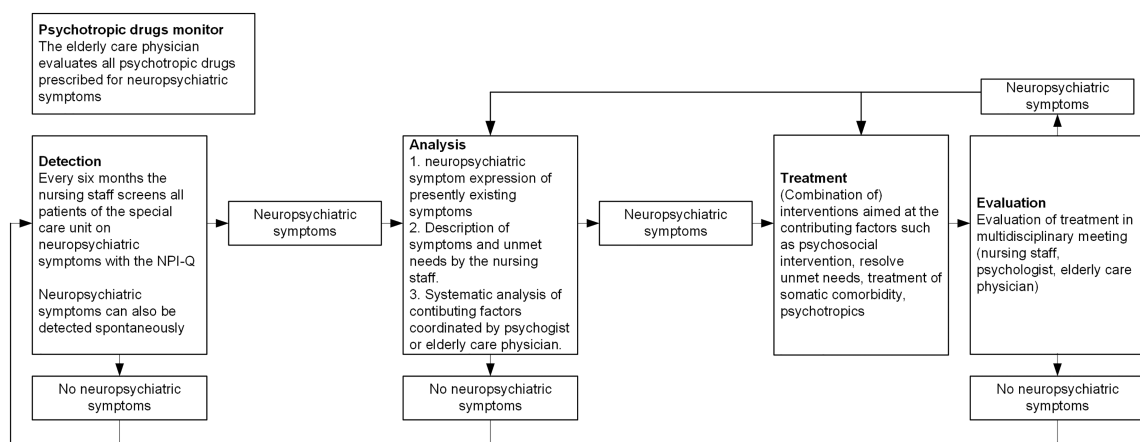


FIGURE 1 The five steps of the care program "Grip on NPS in institutionalized people with YOD."²⁶ Note. Reprinted with permission

either the health care psychologist or the elderly care physician or discusses the symptoms in a multidisciplinary meeting. The health care psychologist and/or elderly care physician perform an analysis together with the nursing staff and, if necessary, establish a treatment plan. The treatment is evaluated in multidisciplinary meetings. However, there are many differences in the extent to which these steps are performed in nursing homes. For instance, the evaluation of the treatment of NPS with standardized instruments might not be performed every time.

2.5 | Data collection and ethical considerations

The data were collected retrospectively; at each time-point, the research assistants contacted the participating YOD SCUs by telephone for collecting data regarding unit size, number of beds, number of residents, the number of full-time equivalents on the unit, and staff absenteeism. The data on staff absence were delivered by the Human Resources Management department of the nursing home. Psychotropic drug use was derived from the resident's medical file. The data on time investment of the elderly care physician and health care psychologists were collected on T1 and T3 by means of a diary.

2.6 | Ethical considerations

The BEYOND-II study protocol was approved by the Medical Ethics Committee region Arnhem/Nijmegen (file number: 2015-1558). This research project was conducted according to the principles of the Declaration of Helsinki (version November 2013, www.wma.net) and is in agreement with the law regarding medical-scientific research in humans. Written informed consent was obtained from the legal representative of each resident.

2.7 | Cost outcomes

The costs were analyzed from a health care perspective. The costs of staff absence, psychotropic drug use, and time investment of the elderly care physician and health care psychologist were included. Changes in costs were expected to be observable after the SCU had been exposed to the intervention condition for 6 months. For the calculation of costs, we adhered to the "Manual for Healthcare Costs Analysis" provided by Zorginstituut Nederland.²⁹

The costs of staff absence were based on the percentage of nursing staff absence of the total number of full-time equivalents on the SCU. The costs of the number of full-time equivalents were based on the mean hourly wages per full-time equivalent of nursing staff working in nursing homes.

The costs of time investment of elderly care physicians and health care psychologists on the management of NPS were estimated using diaries. For 3 weeks, the amount of time in minutes spent on the management of NPS for each resident was registered. This included physical/psychological examination, consultation, and treatment. Time spent on the management of NPS was multiplied with the mean salary

per hour of these professionals and extrapolated to 6 months. The time invested by the nursing staff was not registered because throughout their shift, nursing staff continuously spend time on the prevention and management of NPS making it difficult to separate time spend on NPS from time spend on other tasks.

The costs of the educational program were calculated as follows: The educational program and the follow-up training after 6 months covered in a total of 5.5 hours, and this was multiplied with the mean salary costs per discipline per hour and divided by the number of residents on the YOD SCU. The mean salary costs per discipline were derived from the Dutch collective labor agreement for professionals working in nursing homes.³⁰

The data about the use of psychotropic drugs were derived from the nursing home pharmacist's electronic prescription system. Psychotropic drugs prescribed *pro re nata* were discarded. Per prescription, the Anatomical Therapeutic Chemical code, dosage, and frequency (daily, weekly, and monthly) were registered. The dosage was registered as a total dosage per day, week, or month. The pharmaceutical price of the psychotropic drugs was retrieved from the website www.medicijnkosten.nl. Generic product prices were used because our intervention is not expected to influence the choice of brands. The costs per prescription were summed into total costs of psychotropic drugs per resident, per half year.

Composite cost measure contained the sum of costs of staff absenteeism, costs on psychotropic drugs, and costs of the educational program.

3 | STATISTICAL ANALYSIS

All analyses were performed using SPSS version 25. The analyses included all residents and staff members of whom we had information for at least one period. All outcomes were checked for missing values, normality, and outliers. Missing values were present on the outcomes "costs of staff absenteeism" and "costs of time investment of the elderly care physician and health care psychologist." Missing values on the outcome "costs of staff absenteeism" were considered to be missing (completely) at random and imputed using the median costs in both study conditions. Regarding "costs of time investment of the elderly care physicians and health care psychologist," more than 50% of all values were missing (not completely at random), and therefore, imputation was not sensible to perform. Therefore, only the mean time and mean costs of the professionals on available data were described. Costs of psychotropic drug use were analyzed at the resident level, whereas costs of staff absenteeism and the composite cost measure were analyzed at the unit level. The effects of the intervention on the costs at unit level were investigated using linear mixed models with a random effect for YOD SCU to take into account correlation of the repeated measures over time of the costs at unit level. If costs were measured at resident level, additionally, a random effect of resident nested within unit was included. With this model, we estimated the main effect of the intervention and the main effect of time (fixed effect for intervention and fixed effects for three categorical

time points). The costs of the educational program were included in the composite cost measure. In all analyses, a *P* value of <.05 was considered statistically significant.

4 | RESULTS

In total, 274 NH residents with YOD participated in this study divided over 13 nursing homes throughout the Netherlands. The mean number of beds on the SCU was 25 (SD: 11). On average, 24 nursing staff members were working on the SCU, with an average full-time equivalent of 21.84 (SD: 15.3). At baseline, the costs were on average €1709.67 and consisted of the costs of psychotropic drug use, which were on average €35.48 per resident per half year, and costs of staff absenteeism which were on average €1674.80 per resident per half year (Table 1).

TABLE 1 Costs per resident using care as usual (*n* = 207)

	Mean (SD) in EUR	Range in EUR
Psychotropic drugs	35.48 (56.81)	0-376.38
Staff absenteeism	1674.80 (183.30)	0-8937.55
Composite cost measure ^a	1709.67 (183.49)	0-9084.61

^aAt baseline, the costs of the educational program were €0.

TABLE 2 Costs per resident per half year for the time investment of elderly care physicians and psychologists regarding the management of NPS

	Care as Usual	Intervention
Elderly care physician		
<i>n</i>	64 residents	74 residents
Involvement of professional	43.7%	64.9%
Mean time investment	69 (79) minutes	40 (52) minutes
Mean costs (SD)	292.52 (605.40)	255.73 (445.45)
Health care psychologist		
<i>n</i>	72 residents	133 residents
Involvement of professional	54.2%	51.1%
Mean time investment	56 (54) minutes	72 (144) minutes
Mean costs (SD)	207.32 (330.90)	253.37 (745.72)

TABLE 3 Effects of the intervention and time-effects on costs

	Intervention		T1		T2		T3	
	Estimate	95% CI	Estimate	95% CI	Estimate	95% CI	Estimate	95% CI
Costs of psychotropic drugs	-13.65	-29.92 to 2.61	3.88	-10.51 to 18.27	19.05*	1.96 to 36.14	15.36	-5.75 to 36.74
Costs of staff absence	-16.95	-438.51 to 404.61	-29.99	-383.75 to 323.77	159.11	-262.96 to 581.19	331.12	-199.29 to 861.53
Composite cost measure	161.77	-257.70 to 581.24	-36.27	-388.28 to 315.74	94.34	-325.64 to 514.33	225.83	-301.96 to 753.61

Note. All costs are in EUR.

**P* < .05.

4.1 | Costs of the time investment of the professionals

The data on the time and costs of time investment regarding the management of NPS showed that with care as usual, the elderly care physician was involved in 43.7% of the residents. This increased to 64.9% of the residents after working with the intervention for 6 months (Table 2). The mean costs of the time of investment of the elderly care physician in the care decreased from €292.52 (SD €605.40) at the time the care program was not yet used to €255.73 (SD €445.45) when the intervention was in use.

The health care psychologist was involved in 51.1% of the residents, and this remained more or less equal after working with the intervention for 6 months (54.2%). The mean costs of the time investment of the health care psychologist increased from €207.32 (SD €330.90) to €253.37 (SD €745.72) when using the intervention.

4.2 | Results of the intervention on costs

With regard to the effect of the intervention on costs, linear mixed model analyses showed no statistically significant increase in the composite cost measure. No significant time effects were found for the composite cost measure. There was no statistically significant effect of the intervention on the costs of staff absenteeism, also no statistically significant time effects were found. There was no statistically significant effect of the intervention compared with care as usual on the costs of psychotropic drugs. A statistically significant increase in the costs of psychotropic drugs were found 1 year after baseline (T2 estimated effect: €19.05, *P* = .029, 95% CI, 1.96-36.14). The costs for the educational program offered to all staff on the SCU were on average €174.13 (SD € 38.63) per resident (Table 3).

5 | DISCUSSION

To the best of our knowledge, this is the first study to evaluate the costs of an intervention for the management of NPS in YOD nursing home residents. Although the costs of the time investment of professionals have to be interpreted with caution, it appeared that due to the intervention, there was a shift in costs. The elderly care physician was more often consulted in the intervention condition, yet the average time investment decreased, resulting in lower costs compared with care as

usual. On the contrary, the health care psychologist was consulted equally often in both conditions but with the use of the intervention the time investment and thus costs increased. We found no significant effect of the intervention compared with care as usual on the costs of psychotropic drug use, staff absenteeism, and the composite cost measure. The costs of the educational program offered to all staff members on the special care unit were on average €174.13 per resident.

Although the change in costs of the time investment of the professionals have to be interpreted with caution, this may be related to aspects of the care program focusing on the analysis of unmet needs as a cause of NPS and treatment of NPS with psychosocial interventions, both aspects belong to the profession of the health care psychologist. The effect of the intervention on the costs of these professionals is especially interesting because the amount of time available for the special care unit can be reshifted across the professionals. Furthermore, the guidelines regarding the treatment of NPS prefer psychosocial interventions above treatment with psychotropic drugs. Future studies should therefore aim to investigate the effectiveness of the intervention regarding the time-investment of these professionals with mixed model analysis. Besides that, it should be explored what the effect of the intervention is in terms of shift between time spend by the health care psychologist and elderly care physician.

In the grip on challenging behavior study, which focused on late-onset dementia, a cost-effectiveness study was performed making it difficult to fully compare the results.³¹ The costs of psychotropic drugs significantly decreased in their study; in addition, positive significant effects were found on the use of antipsychotics and antidepressants.²¹ In our study, a nonsignificant decrease in costs of psychotropic drugs related to the use of the intervention was found while over time the costs of the psychotropic drugs increased. This latter finding cannot be related to inflation, as we calculated the costs of all psychotropic drugs afterwards. We have no further explanation for the increase of psychotropic drug costs over time. The average costs of the educational program per resident were slightly higher in their study (€190) than in our study (€174.13).

The main strength of our study is that we included a large group of nursing home residents with YOD. However, our study also has limitations. First, all participating nursing homes were affiliated with the Dutch YOD knowledge center, and as such, these nursing homes may already have more specialized knowledge and working methods regarding the treatment of NPS in YOD compared with other nursing homes. Second, there was a high percentage of missing data on the outcome time investment, making it impossible to perform a mixed model analysis on this outcome. As a result, we also had to exclude this outcome from the calculation of the composite cost measure. Regarding the time investment on the management of NPS, most professionals reported that the diary was too time consuming and there was too little time available next to their normal work. It is possible that the professionals that did report time investment represent a select group. Also, we were not able to assess the time investment of nursing staff on the management of NPS. Furthermore, despite the use of electronic client files in the nursing homes and the use of a web-based care program, it was not possible to automatically record

the time investment regarding the management of NPS, for instance, time needed to complete the digital forms. Even though this would not have given us full overview of the time investment, it would have given us insight on the time investment regarding (multidisciplinary) meetings and registration. Lastly, due to the stepped wedge design, not all special care units used the intervention for an equally long period of time. This varied between 6 and 18 months. In case of extreme behavior, it may take longer than 6 months before an effective treatment has been established and changes in costs are noticeable. This may have resulted in an underestimation of the effects. Lastly, the results of this study can only be generalized to countries in which a physician and psychologist are involved in the nursing home care for people with dementia.

In conclusion, the intervention resulted in almost the same amount of cost compared with care as usual. The costs differences between care as usual and the use of the intervention are mostly related to the costs of the educational program which could not entirely be offset by savings in cost of psychotropic drugs and staff absence. Furthermore, as published earlier, we found no effect of the intervention compared with care as usual on agitation and aggression and other NPS and psychotropic drug use.²² However, in our view, the intervention is still of interest for nursing homes in need for methodological and structured approach towards the management of NPS in YOD residents. Managing NPS is complex and although multiple guidelines are available, adhering to these guidelines is difficult. Besides that, these guidelines do not specifically address YOD nursing home residents. The intervention for the management of NPS in YOD nursing home residents is a practical translation of the guidelines in which the involvement of the professionals is predefined, and the focus is on psychosocial treatments instead of treatment with psychotropic drugs. Therefore, considerations other than costs may determine if nursing homes want to implement the intervention for the management of NPS in YOD nursing home residents.

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The data that support the findings of this study are available from the corresponding author upon reasonable request.

CONFLICT OF INTEREST

None declared.

ORCID

Jeannette C.L. van Duinen-van den Ijsel  <https://orcid.org/0000-0003-4925-8232>

Britt Appelhof  <https://orcid.org/0000-0001-5361-4143>

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